

MND Genies

Motor Neurone Disease NSW

A closed Facebook group

For people who have a motor neurone disease related genetic mutation, but do not have MND



"The idea of MND Genies came about as there are supports and trials available for people who currently have MND, but for those with the genes it's like they are sitting ducks waiting for the gene to activate with no support available. Just knowing someone who is in the same boat as you can make the world of difference"

Jessica, Kaitlin and Rebecca

Are you an MND Genie?

About 10% of people diagnosed with MND have a familial form of the disease. Of these, about one in five have a mutation on the SOD1 gene and about two in five have a mutation on the C9ORF72 gene. These mutated genes can be passed down through families and children can inherit the mutated gene.

The aim of MND Genies is to provide a space where people can connect and share their experience of having an MND related genetic mutation.

For more information

To join MND Genies or for more information about the group contact MND NSW at:
mndgenies@mndnsw.asn.au or
ph. 02 8877 0999

@mnd_genies

